

CS FOR SENATE BILL NO. 217(HES)

IN THE LEGISLATURE OF THE STATE OF ALASKA

TWENTY-THIRD LEGISLATURE - SECOND SESSION

BY THE SENATE HEALTH, EDUCATION AND SOCIAL SERVICES COMMITTEE

Offered: 1/30/04

Referred: Judiciary

Sponsor(s): SENATOR OLSON

A BILL

FOR AN ACT ENTITLED

1 **"An Act relating to genetic privacy."**

2 **BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF ALASKA:**

3 * **Section 1.** The uncodified law of the State of Alaska is amended by adding a new section
4 to read:

5 LEGISLATIVE FINDINGS; PURPOSES. (a) The legislature finds that

6 (1) the deoxyribonucleic acid (DNA) molecule contains information about the
7 probable medical future of an individual and the individual's blood relatives; this information
8 is written in a code that is rapidly being deciphered;

9 (2) genetic information is uniquely private and personal information that
10 generally should not be collected, retained, or disclosed without the individual's authorization;

11 (3) the improper collection, retention, or disclosure of genetic information can
12 lead to significant harm to an individual and the individual's blood relatives, including
13 stigmatization and discrimination in areas such as employment, education, health care, and
14 insurance;

15 (4) an analysis of an individual's DNA provides information not only about

1 the individual, but also about blood relatives of the individual, with the potential for affecting
2 family privacy, including reproductive decisions;

3 (5) current legal protections for medical information, tissue samples, and DNA
4 samples are inadequate to protect genetic privacy and the individual's property interest in
5 these samples and the information derived from the samples; and

6 (6) laws for the collection, storage, and use of identifiable DNA samples and
7 private genetic information obtained from those samples are needed both to protect individual
8 and family privacy and to permit and encourage legitimate scientific and medical research.

9 (b) The purposes of this act are as follows:

10 (1) to define the rights of individuals whose genetic information is collected,
11 analyzed, retained, or disclosed and the individual's property right in that information;

12 (2) to define the circumstances under which an individual may be subjected to
13 genetic testing; and

14 (3) to define the circumstances under which an individual's genetic
15 information may be collected, analyzed, retained, or disclosed.

16 * **Sec. 2.** AS 18 is amended by adding a new chapter to read:

17 **Chapter 13. Genetic Privacy.**

18 **Sec. 18.13.010. Genetic testing.** (a) Except as provided in (b) of this section,

19 (1) a person may not collect a DNA sample from a person, perform a
20 DNA analysis on a sample, retain a DNA sample or the results of a DNA analysis, or
21 disclose the results of a DNA analysis unless the person has first obtained the
22 informed and written consent of the person, or the person's legal guardian or
23 authorized representative, for the collection, analysis, retention, or disclosure;

24 (2) a DNA sample and the results of a DNA analysis performed on the
25 sample are the exclusive property of the person sampled or analyzed.

26 (b) The prohibitions of (a) of this section do not apply to DNA samples
27 collected and analysis conducted

28 (1) under AS 44.41.035 or comparable provisions of another
29 jurisdiction;

30 (2) for a law enforcement purpose, including the identification of
31 perpetrators and the investigation of crimes and the identification of missing or

1 unidentified persons or deceased individuals;

2 (3) for determining paternity;

3 (4) to screen newborns as required by state or federal law;

4 (5) for the purpose of medical or scientific research and education,
5 including retention of genetic information and samples from anonymous donors if the
6 anonymous donor was informed at the time of collection of the sample that the sample
7 would be used for anonymous research and education and the donor consented to the
8 collection and use of the sample at that time;

9 (6) for the purpose of emergency medical treatment.

10 (c) A general authorization for the release of medical records or medical
11 information may not be construed as the informed and written consent required by this
12 section. The Department of Health and Social Services may by regulation adopt a
13 uniform informed and written consent form to assist persons in meeting the
14 requirements of this section. A person using that uniform informed and written
15 consent is exempt from civil or criminal liability for actions taken under the consent
16 form. A person may revoke or amend their informed and written consent at any time.

17 **Sec. 18.13.020. Private right of action.** A person may bring a civil action
18 against a person who collects a DNA sample from the person, performs a DNA
19 analysis on a sample, retains a DNA sample or the results of a DNA analysis or
20 discloses the results of a DNA analysis, in violation of this chapter. In addition to the
21 actual damages suffered by the person, a person violating this chapter shall be liable to
22 the person for damages in the amount of \$5,000 or, if the violation resulted in profit or
23 monetary gain to the violator, \$100,000.

24 **Sec. 18.13.030. Criminal penalty.** (a) A person commits the crime of
25 unlawful DNA collection, analysis, retention, or disclosure if the person knowingly
26 collects a DNA sample from a person, performs a DNA analysis on a sample, retains a
27 DNA sample or the results of a DNA analysis, or discloses the results of a DNA
28 analysis in violation of this chapter.

29 (b) In this section, "knowingly" has the meaning given in AS 11.81.900.

30 (c) Unlawful DNA collection, analysis, retention, or disclosure is a class A
31 misdemeanor.

1 **Sec. 18.13.100. Definitions.** In this chapter,

2 (1) "DNA" means deoxyribonucleic acid, including mitochondrial
3 DNA, complementary DNA and DNA derived from ribonucleic acid;

4 (2) "DNA analysis" means DNA or genetic typing and testing or any
5 test for determining the presence or absence of genetic characteristics in an individual,
6 including tests of nucleic acids, chromosomes, or proteins in order to diagnose or
7 identify a genetic characteristic;

8 (3) "genetic characteristic" includes a gene, chromosome, or alteration
9 of a gene or chromosome that may be tested to determine the existence or risk of a
10 disease, disorder, trait, propensity, or syndrome, or to identify an individual or a blood
11 relative; "genetic characteristic" does not include family history or a genetically
12 transmitted characteristic whose existence or identity is determined other than through
13 a genetic test.

14 * **Sec. 3.** The uncodified law of the State of Alaska is amended by adding a new section to
15 read:

16 **APPLICABILITY.** AS 18.13, enacted by sec. 2 of this Act, applies to any collection,
17 analysis, retention, or disclosure occurring after the effective date of this Act.